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NHS
South East Coast
Operational Delivery Networks
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Patient Diaries

Standards and guidance for the use of patient diaries in Critical Care

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1. Summary

Patient diaries can be used to help patients understand and come to terms with what has happened to them whilst they have been critically ill. Diaries provide a factual account of what has happened in Critical Care so filling gaps in memory. They provide a context for memories that exist and can help dispel inaccurate and delusional beliefs.

The National Institute of Clinical Excellence (NICE) recommends that rehabilitation following critical illness starts as soon as possible and addresses psychological as well as physical symptoms. Equipping patients with a better understanding of what has happened to them in Critical Care may help to set realistic goals for recovery and minimise the risk of adverse long term problems (NICE 2009).

2. Purpose and scope

These guidelines have been compiled to offer guidance to Critical Care Units within the South East Coast Operational Delivery Network on the use of patient diaries during the process of rehabilitation following critical illness. They provide guidance on standards to be achieved in terms of writing, storage and handover of diaries and in the use of photographs.

Many Critical Care Units have established polices governing the use of patient diaries and it is the purpose of these guidelines to supplement but not supplant those. Similarly, there are a number of formats for patient diaries and it is not the purpose of this document to determine the exact format and content. Specific arrangements for the management and use of diaries should be determined by local policy. All Critical Care Units are encouraged to develop a comprehensive local policy to govern the use of patient diaries in Critical Care.

3. Inclusion

A diary should be considered for any patient who may have difficulty adjusting emotionally to their experience of critical illness. Whilst patients that are sedated and ventilated for three or more days are likely to benefit from a diary, other patients may experience psychological distress and the benefit to them may be no less significant.

Caution should be taken in writing a diary for someone for whom English is not their first language where there is the potential for misinterpretation.

4. Confidentiality and consent

The patient diary is accessible by family and friends and should not contain information confidential to the patient or to close relatives only.

Agreement from the patient that a diary be completed for them should be obtained from the patient whenever possible. The patient will need to be informed of the purpose and potential benefits. A diary must not be commenced when agreement has been refused.

A diary may be commenced without patient agreement when in the best interest of the patient. The potential benefit to the patient permits the writing of a diary when a patient is unable able to express their agreement.

Agreement from the patient for continuation of a diary must be sought at the earliest opportunity and the detail of this agreement recorded. It is accepted that the most appropriate time this may be after the patient has been discharged from Critical Care. The procedure for obtaining and recording patient agreement must be detailed in local policy documents.

5. Management of diaries

The format for the diary can vary from pre printed booklets to a loose sheaf of paper bound together on completion; whatever format chosen the following principles of management apply:

- New diaries should be easily accessible and started promptly for any patient who may benefit.

- Whilst the patient is on the Critical Care Unit the diary should be kept at the patient's bedside for both staff and relatives to complete.

- The patient should be consulted about when they would like to receive their diary and they must be supported through this process. The time frame for this can vary. Some patients may wish to see their diary when they leave Critical Care. Others may need to wait weeks or months before they are ready to absorb the details of their experience.

- The diary, once received, is the possession of the patient. Patients and relatives may find it useful to continue the diary for some time after their discharge from Critical Care.

- Diaries may not be taken outside Critical Care unless in the possession of the patient. There must be a means to store the diary safely and securely within Critical Care until such a time as the diary is given to the patient or declined and destroyed.

- If, after an agreed period of time, the patient does not wish to receive their diary, the diary should be shredded.

- In the event that a patient dies or does not regain capacity the diary can be offered to the relative or loved one. The relative or loved should be offered support through this process. It is advised that photographs are not offered to bereaved relatives due to the lack of patient consent.

- It is recommended that a register be kept to keep record of:

    - for whom and when a diary is commenced
    - date and location of patient discharge from ICU
    - when the diary is received by the patient or when it is destroyed
    - details of any photographs taken and where they are stored or when they are given to the patient
    - patient or next of kin contact details

6. Content

What to write in a diary is a concern for many staff. The simple rule is that anything you are prepared to tell the patient, and that the patient is willing to share with family and friends, you can write down. Relatives should be encouraged to contribute to the diary as much as they can but they are often not able to give the detail of events that gives meaning to vague memories.

All staff in the multi-disciplinary team should be encouraged to contribute to the diary to give it added depth and meaning. Factual detail on the patient's condition and observation of their behaviour and environment can all be helpful.

The diary should clearly state the patient's name and date of birth and a first entry should include a description of the reason for admission. It is helpful to note the date and time of events and to write the diary, when possible, in sequential order. Jargon and abbreviations should be avoided, as they should be with any communication with patients and relatives. Similarly, avoid information confidential to the patient as others will read the diary.

7. Photographs

Photographs are a powerful means of helping patients understand what has happened to them and can enable patients to put their experience and ongoing recovery into perspective.

Agreement for the taking of a photograph should be obtained from a patient whenever possible. The patient will need to be informed of the purpose and potential benefits. A photograph must not be taken when agreement has been refused.

A photograph may be taken without patient agreement when in the best interest of the patient. The potential benefit to the patient permits the taking of a photograph of a critically ill patient at a time when they are not able to express their agreement.

A photograph must not be used without patient agreement. Photographs must not be entered into a diary until the patient has seen the photograph and expressed their agreement. The detail of this agreement should be documented. The procedure for obtaining and recording patient agreement must be detailed in local policy documents.

Photographs must not be given to family or friends. The taking of photographs by professional staff does not grant permission for family and friends to do so.

An initial photograph when a patient is sedated and ventilated is recommended. Subsequent photographs can be taken to show stages of recovery and the layout of the bed space and Critical Care Unit. A photograph can be taken at any time when it may help the patient understand what has happened to them.

A relative or member of staff may be photographed with the patient if they wish and their agreement is obtained.

Photographs may be taken in Polaroid or digital format. Secure labelling and storage of photographs will depend on the method chosen and should be stipulated in local policy documents.

8. Patient support

The diary should be given to the patient at a time of their choosing. The content of the diary has the potential to be distressing in the short term and patients need to be supported throughout. The content should be explained to the patient and time given for questions and clarification.

An information leaflet for patients and relatives that explains the use of diaries and their benefits is a useful adjunct to ensuring patients and relatives are fully informed.

9. Education

Critical Care staff should receive sufficient information to understand the benefit of a diary and be competent and confident at writing in them. Supervision by experienced staff will enhance the quality of writing and increase confidence.

An online training package for the use of diaries, including a video of a patient and his wife talking about their diary experience can be found at:

https://app.frimleypark.nhs.uk/e-learning/PatientDiaryTraining/launch.html

10. Reference & Acknowledgement

National Institute of Clinical Excellence (2009) Rehabilitation after Critical Illness.
www.nice.org.uk/CG83

The following are acknowledged in providing resource for the basis of these guidelines:
Michelle Sowden, Consultant Clinical Psychologist
Frimley Park Hospital ICU Patient Diary Guidelines
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North of England Critical Care Network Guidelines for Patient Diaries